



Alzheimer Scotland
Action on Dementia

**Response to the Scottish Government
consultation on
Towards a Mentally Flourishing Scotland:
The Future of Mental Health Improvement
in Scotland 2008-11**

1. Introduction

- 1.1. Alzheimer Scotland is Scotland's leading dementia charity. We work to improve the lives of everyone affected by dementia through our campaigning work and through facilitating the involvement of people with dementia and carers in getting their views and experiences heard. We provide specialist services in over 60 locations and offer information and support through our 24 hour freephone Dementia Helpline, our website (www.alzscot.org) and our wide range of publications.
- 1.2. There are currently 58,000 - 65,000 people with dementia in Scotland, 1,350 – 1,650 of whom are under 65. Dementia is a long-term condition which gradually and inexorably impairs every aspect of a person's mental function, from memory and decision-making to the activities of daily living and personal care. The complex, unpredictable and progressive nature of the condition mean that dementia has a profound impact both on people with dementia and on those who care for them. The projected 75% rise in numbers of people with dementia within 25 years¹, due to our ageing population, is one of the key health and care challenges which faces Scotland.
- 1.3. We welcome the opportunity to comment on the document and contribute towards the development of the Action Plan.
- 1.4. Our comments relate specifically to the proposals as they affect dementia. People with dementia differ from people with other mental health conditions in significant respects; their illness brings a set of challenges to them and their families which is not shared by those with other mental health conditions. However, they are also vulnerable to other mental health conditions and to a

¹ Alzheimer Scotland (2007) *The Dementia Epidemic*

loss of mental well-being. It is vital that they are explicitly included in national and local actions to address mental health improvement. We do not feel that the document as it stands sufficiently addresses dementia, and we hope that our comments will assist you to remedy this.

2. Main target groups

- 2.1. While we recognise that the list of targeted groups for mental health improvement in paragraph 6.1 is not intended to be exhaustive, it is important that work with people with dementia and with older people generally is given a higher profile. Older people are a key group which is especially at risk of dementia, and people with dementia are at particular risk of depression or mania² and of a number of factors which may impact on mental wellbeing, including poverty and isolation.
- 2.2. We welcome the recognition of people in institutional settings, such as care homes, as an important target group. There are approximately 25,000 people with dementia living in care homes in Scotland, and there is serious concern about the quality of care they receive. Many are undiagnosed³, and are therefore even more likely to lack appropriate care and support.
- 2.3. We are seriously concerned that there is also insufficient focus on older people with regard to promoting mental wellbeing. While there is mention of later life, the emphasis on early years should be accompanied by a similar emphasis on the long-neglected area of mental well-being in later life.
- 2.4. The Review of the National Programme⁴ makes the criticism that 'Work on later life issues appeared to be minimal' and highlights later life issues in its priority areas for attention. Older people are a group at particular risk, and demographic change means that the number of older people is growing, with a projected 75% increase in the number of people with dementia by 2031. The need for mental health improvement interventions for older people and for support to manage conditions such as dementia is therefore also growing rapidly.

² Nilsson et al (2002) Enduring increased risk of developing depression and mania in patients with dementia. *J Neurol Neurosurg Psychiatry* 73(1):40-4

³ Alzheimer Scotland (2007) *The Dementia Epidemic* quotes Scottish Government figures showing that 4,000 people resident in care homes are believed by care staff to have dementia but have no diagnosis. The report also uses epidemiological studies to estimate that a further 8-11,000 care home residents have unidentified dementia.

⁴ Health Scotland (2008) *A Review of Scotland's National Programme for Improving Mental Health and Wellbeing*

3. Shared objectives and actions for local delivery

Promotion

- 3.1. We agree with the proposals on promoting and improving mental health and mental wellbeing and see these as important in supporting people living with dementia to help them experience good mental wellbeing.
- 3.2. Carers of people with dementia are also a group who would benefit from this kind of support: depression affects 30% to 60% of carers of people with dementia⁵.
- 3.3. It is vital that key workers are dementia-literate as well as mental health and mental well-being literate, and this should be explicitly recognised in the strategy.
- 3.4. There needs to be recognition that the terminology used in mainstream mental health is not always the same as that used in the dementia field – for example the term ‘recovery’ does not have the same level of acceptance and may be misunderstood.
- 3.5. The proposed focus on children and young people should not be to the exclusion of older people.

Prevention

- 3.6. It is important that specific attention is paid to the risk factors for dementia, although the timescale involved may mean that it is many years before the impact may be seen. There is good and increasing evidence that behaviours and lifestyle choices in middle age (including diet, physical activity, mental stimulation, social activity, smoking) affect the risk of developing dementia in later life. Given the predicted 75% increase in cases of dementia by 2031, immediate action is needed to minimise the impending dementia epidemic.
- 3.7. For people who have a diagnosis of dementia and for their carers, good anticipatory care is vital in avoiding unnecessary problems and crises. Dementia-specific capacity building, training and self-help work aimed at individuals, groups and communities should be made available in order help develop the ability to live well with dementia.

Support

- 3.8. There is strong evidence of the need to tackle both stigma around and understanding of dementia. Alzheimer Scotland is already active in campaigning in both areas and the work needs to continue on a wider scale.
- 3.9. Care needs to be taken that broad messages about mental health do not mislead in relation to dementia – for example, it is not possible to “recover, symptom-free” from dementia, which is a progressive and eventually fatal illness. However, it is possible to live well with a diagnosis of dementia.

⁵ Ballard et al (1996) A follow up study of depression in the carers of dementia sufferers. *BMJ*

- 3.10. The Scottish Dementia Working Group and local involvement groups of people with dementia supported by Alzheimer Scotland have led the way in speaking about the lived experience of people with dementia.
- 3.11. There is a need for support for self-management/self care which is specific to the needs of people with dementia, for example on managing memory loss and diminishing cognitive capacity. The right support for people with dementia in self management will contribute considerably to the aim in paragraph 8.3 of promoting and embedding the 'skills, attributes, belief, values and circumstances that increase resilience, self-efficacy, a sense of mastery, coherence and control, individually and collectively'.

4. Tracking and assessing

- 4.1. Any system for tracking progress and assessing performance needs to be capable of assessing the specific impact of activities on the mental health and mental well-being of people with dementia, and in the longer term, on the prevalence of dementia.

5. Conclusion

- 5.1. Alzheimer Scotland welcomes the broad direction of 'Towards a Mentally Flourishing Scotland'. Mental health and wellbeing among older people in general and people with dementia in particular has not received sufficient attention to date, and we hope that the Action Plan will follow the recognition by the Scottish Government of dementia as a priority⁶ and redress this.
- 5.2. We would be happy to be contacted for clarification or further discussion of the issues raised in this response.

Kate Fearnley
Health and Community Care Director
27 February 2008

⁶ Scottish Government (2008) *Better Health, Better Care: Action Plan*